



Questions and Answers about Employed Parents Caring for Children with Disabilities: A Sloan Work and Family Research Network Fact Sheet

Introduction

The Sloan Work and Family Research Network has prepared Fact Sheets that provide statistical answers to some important questions about work–family and work–life issues. This Fact Sheet includes statistics about Parents Caring for Children with Disabilities. (Last updated: August 2008)



How many children in the U.S. have special health care needs?

✓ **Fact 1** Nearly 14% of children and youth ages 0–17 in the U.S., or 10,221,439 children, have special health care needs (National Survey of Children with Special Health Care Needs, 2005/2006).

✓ **Fact 2** Nearly 22% of U.S. households have one or more children ages 0–17 with special health care needs (National Survey of Children with Special Health Care Needs, 2005/2006).



Does the prevalence of special health care needs vary by race/ethnicity of the child?

✓ **Fact 1** According to the National Survey of Children with Special Health Care Needs (2005/2006), the prevalence of special health care needs varies by the race/ethnicity of the child. The prevalence is highest among multiracial children (18.0%), followed by non–Hispanic White (15.5%), non–Hispanic Black (15%), American Indian/Alaska Native (14.5%) and Native Hawaiian/Pacific Islander children (11.5%). The prevalence is lowest among Hispanic children (8.3%) and Asian children (6.3%).

✓ **Fact 2** The prevalence of special health care needs among the Hispanic population of children varies significantly depending upon whether English or Spanish is the primary language spoken at home. Among Spanish speakers, only 4.6% of children are reported to have special health care needs, while the prevalence among English–speaking Hispanics more closely resembles that of the population as a whole (13%). These findings are consistent with other studies that examine the prevalence of health conditions among Hispanic children (National Survey of Children with Special Health Care Needs, 2005/2006).



How does raising a child with extraordinary health care needs effect employment?

✓ **Fact 1** The Center for Child and Adolescent Health Care Policy estimates that in any given company in the U.S. approximately 8.6% of employees will be caring for a child under the age of 18 who has special health care needs (Center for Child and Adolescent Health Care Policy, n.d.).



✔ **Fact 2** Nearly 24% of families with children who have special health care needs choose to cut back or stop working (National Survey of Children with Special Health Care Needs, 2005/2006).

✔ **Fact 3** “Among the 2.7 million working family householders raising children with a disability, 2 million or 73.5 percent, worked part or all of 1999. The employment rate was 82.4 percent from all householders raising children and 83.3 percent for householders raising children without a disability” (U.S. Census Bureau, 2000).

✔ **Fact 4** In a survey of parents caring for children with serious emotional and behavioral disorders about their employment experience, nearly half of all respondents (48%) reported needing to quit a job at some time to care for their children with mental health disorders, and 27% were terminated because of work disruptions related to their child care responsibilities. At the time of the survey, 17% of the respondents indicated that they were unemployed, and 11% said they could not find employment because of exceptional care demands (Rosenzweig & Huffstutter, 2004).



What is the impact on the employment rate of mothers who care for their children with special health care needs?

✔ **Fact 1** “Having a child with an unstable condition increases the odds of a mother cutting her hours of employment by two and a half times” (Leiter et al., 2004).

✔ **Fact 2** Having a child with a disability is estimated to reduce maternal employment by 6.5% for wives and 10% for female heads of household when controlled for maternal health, according to 1992 national school enrollment data and the Survey of Income Program Participation (Powers, 2001).

✔ **Fact 3** In a national survey of families with children with special needs, 18% of mothers reported that they provide 20 or more hours of in-home health care to their children each week (Leiter et al., 2004).

✔ **Fact 4** “Mothers of [children with special health care needs] may assume the role of health care provider, performing daily caregiving tasks that were once provided primarily in hospitals or other health care settings” (Leiter et al., 2004).

✔ **Fact 5** “Mothers who provide significant amounts of specialized care to their children may even develop ‘informal careers’ (Olesen, 1989), whereby their caregiving becomes an occupation” (Leiter et al., 2004).

✔ **Fact 6** Mothers of white children who have special needs are more likely to reduce their work hours. Maternal education, or having a college degree, also was a significant predictor of stopping work altogether (Leiter et al., 2004).



What is the financial impact of having children with special health care needs?

- ✔ **Fact 1** More than 18% of families who have special health care needs said that their children's health conditions caused financial problems for the family (National Survey of Children with Special Health Care Needs, 2005/2006).
- ✔ **Fact 2** "Families raising children with a disability had a poverty rate of 21.8 percent, compared with 12.65 percent for families raising children without a disability" (U.S. Census Bureau, 2000).
- ✔ **Fact 3** "Families raising children with a disability had a median income of \$38,332, compared with \$39,515 for families with any members with a disability and \$48,936 for all families raising children without disabilities" (U.S. Census Bureau, 2000).
- ✔ **Fact 4** "Across disability types, families raising children with a mental disability reported a median income of \$39,353, compared to \$34,603 and \$32,265 for families raising children with a sensory disability or with a physical disability, respectively" (U.S. Census Bureau, 2000).

The Network has additional resources related to this topic.

1. Our database of academic literature contains the citations and annotations of literature related to the issue of Parents Caring for Children with Disabilities. You can connect to this database at:
http://library.bc.edu/F?func=find-b-0&local_base=BCL_WF



References

Center for Child and Adolescent Health Care Policy. (n.d.) Employee benefits study: Children with special needs and the workplace. Retrieved from
http://massgeneral.org/children/professionals/ccahp/empl_benefit_study/ccahp_empl_benefits_study_work.aspx.

The Center for Child and Adolescent Health Care Policy set out to understand how employees and companies are impacted by childhood disability. The center hypothesized "If 20% of families have a child with a chronic health condition, then we can expect that in any given company, about 8.6 percent of its workforce will be caring for children with special needs (.43 * .20)." Additionally, the center estimates that a "large company with 30,000 employees has approximately 2,580 employees caring for one or more children with special health care needs," "a mid-sized company with 2,000 employees has approximately 172 employees caring for children with special health care needs," and "a small company with 500 employees has about 43 employees caring for children with special health care needs."

Leiter, V., Krauss, M. W., Anderson, B., & Wells, N. (2004, April). The consequences of caring: Effects of mothering a child with special needs. *Journal of Family Issues*, 25(3), 379-403.



"Data are drawn from the Family Partners Project, initiated in 1997 as a collaborative enterprise between the Heller School at Brandeis University and Family Voices, a national advocacy organization of families of children with special needs. The project included a survey, conducted in 20 states, of families of children with special needs concerning their children's medical and therapeutic needs and their experiences with health care plans and other service providers." Surveys yielded a 41% response rate of eligible families and a data set of 2,220 children and their families: 88% of the respondents were mothers, 7% were fathers, and 5% were grandmothers.

National Survey of Children with Special Health Care Needs, 2005/2006, <http://www.cshcndata.org/Content/Default.aspx>.

Approximately 47,000 interviews were completed: 41,000 in a state-level main sample, and 6,000 in a national-level referent sample. Interviews were conducted in English, Spanish, Cantonese, Mandarin, Korean, and Vietnamese.

Powers, E. T. (2001, May). New estimates on the impact of child disability on maternal employment. *American Economic Review Papers and Proceedings* (pp 135–139).

Data are based on the School Enrollment Supplement to the October 1992 Current Population Survey, a large data set containing information on children's specific health impairments and the impact of these impairments on the child's ability to learn. To control for maternal health, Powers imputed the maternal health status data from the Survey of Income Program Participation.

Rosenzweig, J. M., & Huffstutter, K. (2004). Disclosure and reciprocity: On the job strategies for taking care of business and family. *Focal Point: A National Bulletin on Family Support and Children's Mental Health*, 18(1), 4–7.

The data represent 349 parents caring for children with serious emotional and behavioral disorders who responded to the Parent Employment Experiences Survey.

Wang, Q. (2005, July). Disability and American families: 2000: Census 2000 Special Reports. Retrieved from <http://www.census.gov/prod/2005pubs/censr-23.pdf>.

"The survey design is a continuous series of national panels, with sample size ranging from approximately 14,000 to 36,700 interviewed households. The duration of each panel ranges from 2 ½ years to 4 years. The SIPP sample is a multistage-stratified sample of the U.S. civilian noninstitutionalized population. For the 1984–1993 period, a new panel of households was introduced each year in February. A 4-year 1996 panel was introduced in April 1996; a 3-year panel was started in February 2000 but cancelled after 8 months for budget reasons; and a 3-year panel was introduced in February 2001. The 2 ½ year 2004 SIPP sample was started in February 2004 and is the first SIPP panel to use the 2000 decennial-based redesign of the sample" (<http://www.census.gov/sipp/overview.html>).
